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THE UNIVERSITY OF ALBERTA

ASSESSING THE NEED FOR ADULT DAY CARE FOR THE HOMEBOUND ELDERLY

BY

BARBARA D. WILSON

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of MASTER OF ARTS.

IN

RECREATION

DEPARTMENT OF RECREATION AND LEISURE STUDIES

Edmonton, Alberta

FALL 1991

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FACULTY OF GRADUATE STUDIES AND RESEARCH

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Dr. L. Wankel

Dr. A. Neufeld

Dr. S. Mohsen

To My Parents

ABSTRACT

This thesis assessed the need for adult day care services in Calgary, Alberta from the point of view of the homebound elderly people living in the community. It also explored the relationship between health, morale and leisure satisfaction.

A sample of 55 homebound elderly people was interviewed in-person by older adult volunteers. Data was gathered which described the respondents' socio-demographic characteristics, functional status (OARS Activities of Daily Living Scale), caregivers, leisure, morale (Philadelphia Geriatric Centre Morale Scale), perceived need for adult day care and expectations of adult day care.

Respondents generally reported functional informal support networks augmented by formal services. The most frequently reported deficit area was a lack of emotional support. The sample demonstrated a significantly lower incidence of leisure satisfaction than the average population of seniors living in the community. Leisure satisfaction was found to be correlated with morale and functional status but not with perceived health. Poor health was considered to be the greatest barrier to increasing leisure involvement and to accessing adult day care services.

Analysis of a composite score from a number of variables indicated that 63.6 percent of the sample perceived a need for adult day care services. Target groups identified as particularly requiring these services were those who were moderately impaired and/or those stating a need for respite care. However, respondents described many unique and diverse reasons for requiring day programs. The majority

of respondents expected adult day care programs to be community based and to offer primarily leisure services supported by ancillary health care services. Thirteen recommendations, based on the results of this study, are offered to direct the development of a client-focused system of adult day care programs.

The results of this study are utilized to interpret current low user rates of adult day care services and offer suggestions for improving service delivery. The study expands the limited information about the homebound elderly and how they perceive their quality of life.

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CHAPTER 1

INTRODUCTION

This thesis addresses the need for adult day care programs in the city of Calgary. The topic will be presented from the point of view of the potential clients- the homebound elderly, not that of the caregiver or the professional.

A basic assumption underlying this study is that personally rewarding leisure contributes significantly to a person's quality of life. Advanced age and chronic disabilities tend to restrict the leisure and social opportunities of the homebound elderly (Padula 1985). Adult day care is a type of service which has the potential to reduce these restrictions. By facilitating leisure involvement and in turn leisure satisfaction, adult day care may positively influence the morale and life satisfaction of the homebound elderly.

Adult day care has been proposed as a service which will help the impaired elderly to remain functioning in the community as independently as possible for as long as possible (Interdepartmental Committee on Long Term Care 1987). The general purposes of adult day care are: to improve or maintain the existing functioning levels of clients; to provide relief to caregivers; to delay or prevent institutionalization; and to improve quality of life (Padula 1983). It is evident that the purposes of adult day care currently receiving the most attention from government and health care agencies are respite and decreasing the costs of institutionalization (Interdepartmental Committee on Long Term Care 1987). A basic assumption of the current thesis, however, is that if the philosophy of provision is not client focused, gains will only be short-term. The burden of care will only be

relieved temporarily because the underlying factors contributing to that burden will not have been addressed.

This position is based on a body of literature in the fields of gerontology and leisure studies which suggests that physical, emotional and mental health in old age are linked to opportunities which allow the elderly to experience choice and control in their lives (cf., Langer and Rodin 1976; Schultz 1976; Cohen 1988; Collopy 1988). This thesis is based on a social-environmental perspective of aging in which adaptation and self-fulfillment are seen as both active and reactive, as being negotiated by people in their efforts to master a situation while extracting what they need to maintain a positive self-concept (Dowd 1975). Within this perspective, adult day care is viewed as a proactive measure to empower homebound elderly individuals and reduce their dependency on others. In order to develop a system of adult day care which has this client focus, it is essential to determine from the homebound elderly directly what they perceive their needs to be.

Statement of the Problem

This thesis is a descriptive study of the needs, feelings and expectations of a sample of the homebound elderly in Calgary, Alberta regarding adult day care services. A second purpose of the study is to describe the relationship between leisure satisfaction, health and morale in the lives of these homebound elderly respondents. This information is utilized to formulate recommendations concerning the development of adult day care programs and services. The following specific research questions provided a framework for the development of the study and the analyses of the data:

1. What are the socio-demographic characteristics of the homebound elderly in Calgary?
2. What are the leisure lifestyle characteristics of the homebound elderly respondents?
3. What are the target groups for adult day care?
4. What are the expressed needs of the homebound elderly respondents?
5. What are the expressed feelings and expectations of the homebound elderly regarding adult day care services?
6. Is there a relationship between leisure satisfaction, perceived health and morale in the lives of the homebound elderly?

Definition of Terms

The following terms warrant explicit definition to ensure consistency in useage throughout the study.

Adult Day Care Programs:

An "adult day care program" is defined as an organized group program provided during the day, offering planned social and recreational activities, some personal care, and limited health services (Interdepartmental Committee on Long Term Care 1987). Many older people feel initially threatened by the concept of day care. For the majority, it is their first exposure to such a facility and the idea of leisure oriented programs is unfamiliar. Many are commited to the "work ethic" and view leisure programs as a waste of time. As well, some elders feel threatened by expo-

sure to handicapped adults and deny identification with this group. For these reasons, the term "adult day program" was used throughout the survey with the assumption that it sounds less threatening than "adult day care". This term was defined in the interview schedule by the interviewer for the respondent.

Substantially Homebound Elderly:

This term denotes persons who are generally unable to leave their homes without supervision or assistance. In this study, this term does not include the institutionalized population.

Social Support:

The term "social support" is generally used to describe informal assistance provided by family and friends (Shapiro and Tate 1988). It is recognized that "social support", as used in some of the research literature, is a much more complex and involved concept than is described by this interview schedule. However, for the purposes of this study social support will be described by the size of the network and by the frequency and kind of assistance received by respondents. These components of social support were chosen because they help to assess caregiver burden which is a problem proposed to be addressed by adult day care.

Proxy:

A "proxy" is a family member or caregiver who answers for the respondent who cannot answer for himself or herself.

Target Group:

A "target group" is a group of respondents with similar characteristics towards which a particular service is directed.

Leisure Activities:

One's definition of the term "leisure" is a product of personal experiences and situational/social influences (Iso- Ahola 1980). Therefore, in keeping with the goal of this study to obtain direct input from respondents rather than making assumptions, this term was defined by the respondent according to what he or she perceived as leisure. If the respondent requested clarification of this term, the interviewer would volunteer that leisure could be defined as "what one did in one's spare time".

Leisure Satisfaction:

"Leisure satisfaction" is defined as "the positive perceptions or feelings which an individual forms, elicits or gains as a result of engaging in leisure activities" (Beard and Ragheb 1980, 22). In this study, leisure satisfaction is a term which describes the cognitive and emotional state of an individual who finds his or her leisure to be personally meaningful and rewarding.

Need:

A "need" is a condition requiring supply or relief (Merriam-Webster 1986). Although related to wants or desires, needs are considered more basic in that if they are not met the individual's physical and/or psychological health will be adversely affected. In this study, the homebound elderly respondents were asked questions regarding specific needs which would indicate a need for adult day care.

Service Expectations:

"Expectations" are what one considers to be just, proper, due or necessary (Merriam-Webster 1986). In this study, respondents were asked their expectations of adult day care services.

Significance of the Study

This study has both practical and theoretical significance. First, too often the opinions of caretakers and professionals are used as the sole indicators of the needs and wishes of the very old. Programs and services are designed without adequate input and involvement of the potential clients themselves. A basic assumption underlying this study is that in order to develop an effective and efficient system of adult day care services in Calgary, it is essential to obtain information directly from the frail and homebound elderly about their needs and expectations. In this way, one may also obtain a more accurate estimate of the probable utilization of adult day care programs.

A second contribution of the study will be the provision of insights into reasons why some people do not attend an adult day care program even though they demonstrate an apparent need for such a service. This information may help to explain the current low user rates, and offer suggestions for improvements.

Third, the study has theoretical importance given the lack of information about the homebound elderly and how they perceive their quality of life. The study will reveal important information about these individual's views about: their leisure lifestyles, their feelings about being a burden, their fears of institutionalization, and their personal need to improve and develop. In general, this study will contribute to an understanding of the aging process and it will add to the literature concerning the factors which affect life satisfaction in old age.

Fourth, the study design is unique in the fact that it includes respondents with cognitive impairments in the sample through the use of proxy responses. This is

important given the prevailing assumption that people with moderate dementia should be a specific target group for adult day care.

A recent statement in an Alberta Health working document demonstrates that the provincial government is cognizant of the value of needs assessment:

> Current perceptions of the need for adult day care and respite programs need to be validated and future needs identified (Alberta Health 1990,34).

The results of this study should therefore be of interest both to those who conduct research on aging and those who are providing services, such as adult day care, to the aged in the community.

CHAPTER 2

REVIEW OF RELEVANT LITERATURE

Previous Needs Assessments

The first step in any needs assessment is generally to obtain a population profile of the target group. Therefore, some summary statistics describing the elderly in Alberta are an essential part of this literature review.

The population of Alberta is aging. The rate of increase in the age 65 and over population in the province is greater than than that for the total population. In 1988 there were 205,300 people 65 years of age and older in Alberta. This accounted for 8.6 percent of the total provincial population. However, it is predicted that by the year 2016 seniors will compose 14 percent of Alberta's population (Engelmann 1989). The fastest growing age group is the 85 and older category, which is predicted to almost double in proportion in the next 20 years (Engelmann 1989). This last point is especially significant to this research pertaining to disabled seniors since the rate of disability greatly increases with advanced age.

The most recent Health and Activity Limitation Survey (Statistics Canada 1988) reports that in Alberta 90,240 people age 65 and over are disabled in some way. This constitutes 44 percent of the total population of seniors.[1] The survey shows that 81 percent of these disabled seniors live in private households while the remaining 19 percent live in residential and institutional long term care facilities.

Though Alberta has one of the youngest average populations of any of the Canadian provinces, it has a higher proportion of its elderly citizens living in ex-

---

1 Disabilities in this survey are identified through "Activities of Daily Living" questions.

tended care institutions than any other province in Canada.[2] The Canadian Medical Association "Task Force on the Allocation of Health Resources" (1984) states that a number of the older people in institutions could remain in the community if they were provided with the support systems needed to maintain their independence. It has been suggested (Schwenger and Gross 1980) that the high institutionalization rate of the elderly in Alberta is attributable to the lack of viable alternatives in the province.

This high rate of institutionalization, plus the growth in the seniors' population, suggest a need for developing community support programs to assist moderately impaired elderly people to remain living in the community for as long as possible. Adult day care, the subject of this thesis, is one of these support services.

Once a need has been identified, the next step in an assessment is generally to determine the extent of that need. Estimates of the need for adult day care have generally been based on the opinions of professionals. The Interdepartmental Committee on Long Term Care (1987) asked Home Care managers in each community health district to estimate the percentage of elderly who could use a day support program. The responses varied between districts, but the weighted average was 3.1 percent. In the Background Report, the Committee cautions that this estimate may be too high. It reports that in British Columbia only one percent of the senior population uses day support programs and that the initial estimate of 11.2 days per user per month was much higher than the actual 5.5 days user rate. As well, it reports

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[2] 8.3% of seniors in Alberta reside in extended care institutions according to the Committee on Long Term Care for Senior Citizens, A New Vision for Long Term Care, (Edmonton, Alberta, 1988).

that in Manitoba the continuing care staff overestimated the need for adult day care by as much as 50 percent (Interdepartmental Committee on Long Term Care 1987). In light of these facts, the Committe states:

> If 1.5 percent of the estimated number of seniors, 2700, were using day support programs on average one and one half days per week, 810 spaces would be required (Interdepartmental Committee on Long Term Care 1987, 12).

A report of a survey of physicians in Edmonton and surrounding areas estimated that 9,900 people could benefit from adult day services (Edmonton Nursing Home District No. 24 1988). The stated purposes of this study were to determine: what services were most needed; what were desirable program days and times; which areas of the city had the highest need; and if there was a need for specialized day services. Information about day hospitals and day programs in the city was distributed to respondents along with the questionnaire so the results do not differentiate between these two types of day services.

The results of this survey should be viewed with caution due to the poor response rate (23 percent); the fact that the sample was not random; and the fact that many of the physicians surveyed were not eligible to respond. Many of the physicians in the sample were emergency room doctors, who do not see regular patients, or physicians whose practices do not include many elderly clients. The information is also questionable on the grounds that physicians may not be the best judges of their elderly patients' daily care needs. If one accepts these limitations, physicians reported the most important services of an adult day care program to be: family respite (37 percent), socialization and recreation (25.6 percent), and physical and oc-

cupational therapy (24.7 percent).[3] Physicians also reported a need for specialized services for patients such as the mentally dysfunctioning elderly.

Burtrin (1985) suggests that many adult day care centres in the United States were forced to close because they neglected to do an initial assessment of the community's desire or need for such a service. Burtrin herself completed an assessment of the need for adult day care in a particular community. She found that representatives of government and health care agencies, as well as social workers and physicians wholeheartedly supported the idea. Families, however, had divided opinions on the issue; one half saw adult day care as the answer to their problems and the other half said that either they would not take their family member to such a place or that the elderly person would not want to go. Again, the elderly themselves were not asked directly if they would be willing to attend. A recent survey of adult day care centres in the United States indicated under-utilization of these services (Conrad, Hanrahan & Hughes 1990). The authors state that their findings indicate that there is knowledge and enthusiasm on the part of adult day care providers. However, there is also a lack of awareness by potential clients, professionals and caregivers of the role adult day care may play in the continuum of care for the elderly. Conrad et al suggest that providers market services more effectively and over-enroll on a daily basis.

Too often the needs and wishes of the very old are assessed solely on the basis of the opinions of caregivers and professionals in the field. Elderly people's perceptions of their own needs are often very different than what one might expect.

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[3] The percentages reported here are percentages of respondents who rated this service as high priority on a high, medium, low scale.

For example, Seelback (1984) found that adult children seemed not to appreciate their elderly parents' concerns with crime and safety, or with the difficulties of dealing with bureaucratic agencies. Children, on the other hand, were more concerned about home health care and personal care to which the elderly attached relatively low priority. Tobin and Lieberman (1986) found that many elderly persons would avoid services such as adult day care due to a fear of institutionalization. This fear has considerable implications for the Canadian situation considering the tendancy in this country to locate adult day care programs in long-term care facilities.

Needs assessments also attempt to identify groups which should be targetted for a particular service. A recent government report identifies the target group for adult day care in Alberta as:

> Adults who suffer from a degree of physical and/or mental disability as a result of chronic illness severe enough to make them potential candidates for institutional care (Interdepartmental Committee on Long Term Care 1987).

A current working document dealing with policy and standards for adult day care (Alberta Health 1990) proposes an addendum to this definition to include those who can be discharged earlier from an acute care hospital or long term care institution.

The current philosophy of provision of adult day care holds that these programs should target those "at risk" for institutionalization. Yet, recent studies show that only old age and lack of social supports, not specific health or social variables (Brock and O'Sullivan 1985; Shapiro and Tate 1988), are consistently major predictors of institutionalization. This research supports the need for community day programs for those elderly who do not have a well-developed informal support network. It also indicates that many homebound elderly individuals face

institutionalization for very different reasons. This is further evidence that external assessments may not be the most reliable predictors of the need for adult day care. The self- reported needs and feelings of the potential clients must also be taken into consideration.

Evaluation Studies of Adult Day Care Programs in Alberta

There have been three formal evaluation studies of the following adult day care programs in Alberta: the Victoria Order of Nurses Adult Day Health Care Program- Edmonton; the Lethbridge Senior Citizens Association Day Program; and the Association of Adult Social Day Programmes- Edmonton. The specific services described and the concerns raised in these evaluation studies influenced the choice of questions asked in the interview schedule of this study.

A more recent working document published by Alberta Health (1990) outlines the policy and standards of adult day support and day hospital programs. This document reiterates the point, made earlier in this thesis, that individuals need to be involved in any decisions about the care and services available to them. Only in this way may clients be responsible, independent and in control of their own lives. The document also recommends services which are essential and those which are optional in an adult day support program. Essential services would include assistance with activities of daily living and developing lifeskills, and planned physical, recreational, and social activities. Optional services would include health monitoring, assistance with medications, transportation, dietary services, health education, rehabilitation consultation, and supportive counselling (Alberta Health 1990).

Leisure and Quality of Life

One variable which has been shown to predict life satisfaction in old age is leisure satisfaction (cf., Riddick 1985; Russell 1987; Kelly, Steinkamp and Kelly 1987). Since improving the quality of life of the homebound elderly has been stated as an important purpose of adult day care, the relationship between leisure satisfaction, perceived health, and life satisfaction is significant to this research.

The literature contains many studies which attempt to explain the dynamics of leisure in the lives of the elderly. A survey of the leisure interests of older adults in Calgary found that the general population of seniors is actively involved in leisure pursuits (Calgary Parks and Recreation 1989). The study indicated that 45.3 percent of respondents were very satisfied, 38.2 percent were satisfied, and 7.1 percent were not satisfied with their leisure lifestyles.

Iso-Ahola (1980) suggests that the leisure behavior of many people in later life is motivated by the need for self- esteem and ego integrity. Okun, Stock and Haring (1984) conducted a study which showed that leisure choices in old age are motivated by a need for affiliation and social integration. This study demonstrated that social activities contribute more to the life satisfaction of those over 65 than to that of younger adults. Yet, it is important to note that these leisure environments which are central to overall life satisfaction are drawn into a tighter and tighter circle for the oldest segment of our population. Resource restrictions related to health, income, mobility and physical abilities are more prevalent in the oldest age category (Kelly, Steinkamp and Kelly 1987).

Several studies have shown that participation in leisure activities is an important predictor of life satisfaction even when perceived health is included in the analysis. Riddick (1985) found that of six variables investigated, leisure activities had the strongest positive relationship with life satisfaction. Health was second in importance for females, but third in importance, behind income, for males. Similarly, Russell (1987) found that satisfaction with leisure activities in retirement was more positively related to life satisfaction than was gender, age, marital status, annual income, self-rated health, religiosity, retirement choice, or mobility. In a large study of elderly residents of Peoria, Illinois, Kelly, Steinkamp and Kelly (1987) found that leisure activity level accounted for 13.3 percent of the variance in subjective well-being while social and resource factors (health, marital status, age, education, sex, occupational level) taken together only accounted for 11.8 percent of the variance. Caution must be exercised when considering these results as the samples were all made up of large, non- institutionalized elderly populations. The proportion of frail elderly in the samples was very small and would have little impact on the reported results.

In another study, Lawton and Fulcomer (1987) analyzed the uses of time by four groups of elderly people selected to represent descending levels of competence. They found that liking for activities was greater among those in good health. Good health and functional ability were found to be related to personal adjustment. An investigation of the relationship between participation in leisure activities and the life satisfaction of elderly institutional residents (Agostino, Gash and Martinsen

1981) found a significant positive relationship between being active in group and individual leisure pursuits and life satisfaction.

In the Riddick (1985) study, the author concludes that her model of life satisfaction in old age is too simplistic. She says it would be beneficial to examine how the perceived *quality* of leisure experiences relates to mental health. Similarly, the Russell (1987) study found that frequency of participation in leisure activities had no significant relationship to life satisfaction in retirement, whereas satisfaction with leisure activities did. These comments and results indicate that leisure satisfaction, as opposed to time spent in leisure activities or specific types of activities, would be an important variable to examine in an assessment of the needs of the homebound elderly. They also indicate that leisure satisfaction and perceived health are linked to quality of life in old age.

CHAPTER 3
METHODOLOGY

Sampling Design

The population universe for this study consisted of individuals age 65 and over who had one or more chronic disabilities causing them to be substantially homebound. In 1988, the Civic Census reported that there were 8507 dependent seniors in Calgary, 44 percent (3743) of whom lived in the community.

Though every effort was made to randomly select potential respondents, the sample is not random or representative in the technical sense. A complete list of this target population was not available. Therefore, alternative sampling approaches were employed. As comprehensive a list as possible of the homebound elderly was assembled from the following sources:

1. Calgary Homemaker Service
2. City of Calgary Social Services (Project Home Help, Shopping Services)
3. Parkinson's Society
4. Seniors Assisting Seniors
5. Community Support Services for Seniors
6. Bow Cliff Seniors Outreach Program
7. Outreach Program for Eastern Core Seniors
8. Golden Age Club
9. Independent Referrals

The Calgary Homemaker Service and the City of Calgary Social Services are city-wide service organizations for disabled people. These agencies screened their client lists to identify those people age 65 and over and a letter was sent to 100 randomly selected potential respondents inviting their participation in the study. In the letter, the potential respondents were asked to telephone the researcher. When this was done, an individual's eligibility for the study was determined.

The other seniors' organizations involved were given the eligibility criteria and asked to screen their client lists for those who obviously were not eligible for this study. Agencies were then asked to release the names and phone numbers from their resulting lists. In most cases, an agency representative contacted the potential respondents to obtain their permission to release this information.

Using these two methods of sampling, a composite list of the homebound elderly in Calgary was assembled. In total, some 243 people were contacted. Of these, 93 people responded to the mailouts and agency screenings. During the telephone screening, twenty-eight of these potential respondents were found to be ineligible and eight refused to participate in an interview. The resulting sample of 57 homebound elderly people was interviewed. Two of these interviews were not completed. Therefore, the response rate of the mailout/screening process was 31.7 percent and the response rate of eligible respondents was 59.1 percent. The final sample was composed of 11 men and 44 women ranging in age from 65 to 92 years of age.

Method of Data Collection

The interview method of data collection was chosen for this study. Interviews tend to result in higher, more accurate response rates and they are more personal than surveys (Rossi, Wright & Anderson 1983). Also, given that a large number of the sample would be of advanced age, illiterate, confused, and/or have poor eyesight or hearing, it was felt that the use of self-administered questionnaires or telephone surveys would be inappropriate. The in-person interview method was further warranted to allow a proxy to be present when necessary.

The interview schedule followed a semi-structured format. While the majority of questions utilized closed response categories, some questions provided for an open- ended response and interviewers were instructed to record respondents' comments and opinions.

The interview schedule was developed on the basis of information gathered during the literature review in order to answer the stated research questions. Topics covered in the interview included: socio-demographic characteristics, activities of daily living, caregivers, leisure, morale, perceived need for adult day care, and expectations of adult day care.

Pre-Test

A pre-test of the interview schedule was conducted by two trained interviewers on a non-random sample of four impaired elderly respondents known to be living in the community. Two of the pre-test respondents required a proxy to be present. Feedback was obtained from the interviewers and revisions to the interview schedule were made as necessary.

Contacting Respondents

Potential respondents were contacted by telephone to explain the nature and purpose of the research and to acquire their or their proxy's permission to carry out an interview. At this time the eligibility of the respondent was confirmed. If the respondent was eligible, and the respondent or proxy was willing, an appointment was made to conduct an interview in the respondent's home.

Interviews

Four older adults were trained to conduct the interviews. [4] The training sessions focused on interviewing techniques, disabilities common to the elderly, and maintaining consistency in questioning. Interviewers were randomly assigned to respondents unless a respondent specifically stated that they prefered to have a male or female interview them.

There are many reasons for using older adults as volunteer interviewers. First and foremost, seniors view volunteering as an important leisure activity. This researcher supports the philosophy that research should benefit the community both in its process as well as in its results. Second, seniors tend to be reliable and dedicated volunteers. Third, studies show that the elderly interact more easily and honestly with their peers. Using peer inteviewers may reduce the tendency for respondents to give answers they feel are socially desirable (Research and Planning Unit 1983). Peer interviewers would know best what questions would tend to be

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[4] This interviewing team consisted of two men and two women. 61 percent of the interviews were conducted by the women and 39 percent were conducted by the men.

invasive to their age cohort.. Finally, by avoiding the use of paid interviewers, costs were considerably decreased.

Interviewing took place between December 1, 1990 and January 31, 1991. On average, an interview took 66 minutes to complete.

Instruments

1. Revised Philadelphia Geriatric Centre (PGC) Morale Scale:

An analysis of many measures of morale suggested three consistently reproduced factors in morale among the elderly: agitation, attitude toward one's own aging, and lonely dissatisfaction (Lawton 1975). These revised scale factors have a high degree of internal consistency as determined by Cronbach's alpha: .85, .81 and .85 respectively (Lawton 1975). The resultant 17 item morale scale was used in this research project to measure the life satisfaction of the respondents.

2. OARS Instrumental and Physical Activities of Daily Living Scale:

The OARS Multidimensional Functional Assessment Questionnaire (MFQA) consists of five scales: social resources, economic resources, mental health, physical health, and activities of daily living. This questionnaire can be administered in clinical or survey settings to the subject or somebody who knows the subject well. Ratings range from excellent to totally impaired for each scale (Ninth Mental Measurements Yearbook 1985). The average inter-rater reliability of the MFQA is .77. The average test-retest reliability is .61. The construct validity of this tool is apparent and it demonstrates impressive concurrent validity in that community, clinical and institutionalized samples were easily separated using MFQA scores (Ninth Mental Measuremnts Yearbook 1985). Fillenbaum and Smyers

(1981, 433) in their analysis of this instrument state that "it appears to be the most established of such measures".

Each scale in the assessment may stand alone. The activities of daily living scale used in this study is a standard scale which has been widely employed by nursing and rehabilitation professionals to assess the functioning level of clients. This scale was used in this research project to determine the physical and instrumental functioning levels of respondents. It was chosen because it assesses the abilities which impact the potential for leisure involvement (i.e., the ability to use the telephone), and those which influence services which would be required in adult day care centres (i.e., the ability to bathe oneself).

3. Leisure Satisfaction Index:

A nine-item leisure satisfaction index was created from variables which explored respondents' feelings about their home and community leisure and whether they found their leisure to be interesting and rewarding. These questions were identified by Beard and Rageb (1980) as important measures of leisure satisfaction, and adapted for this survey of older adults. The items in this leisure satisfaction index demonstrated adequate internal consistency (Cronbach's alpha= .67).

4. Need for Adult Day Care Index:

A perceived need for adult day care index was assembled from statements respondents made as to whether they felt they needed such a program, would benefit from such a program, and would attend such a program. This index was found to have a high degree of internal consistency (Cronbach's alpha= .78), ensuring the reliability of the index.

Data Analysis

The following statistical methods were employed in the analysis of the data generated from this study. First, frequency tables were used to analyze variables in the following categories: socio-demographic characteristics, health status, social support characteristics, leisure lifestyle characteristics, and perceptions of adult day care. Percentages were reported to describe these characteristics of the sample (see Chapter 4).

Second, scatterplots were used to classify the leisure satisfaction and morale indices. Variables in the leisure satisfaction index were rated on an integer scale from one to three, where a high score indicated satisfaction. The sample mean leisure satisfaction score was then calculated. A scatterplot of these scores about the mean was analyzed and the sample was statistically clustered into high, medium and low leisure satisfaction groups. The results of this classification are reported on page 43.

Similarly, answers to the morale questions were rated on an integer scale of one to two, where a high score indicated high morale. Using a scatterplot, the sample was clustered into high, medium and low morale groups. These results are reported on page 44. Third, most questions in the interview schedule incorporated non-interval response categories and thus produced non-parametric data. The Chi Square statistic is therefore reported in the results to identify dependent relationships between variables.

Delimitations and Limitations of the Sampling Design

This study is delimited to the population which is specified in the sampling procedure. The reasons for using a sample from a large urban population are mostly practical (convenience, accessibility, etc.). Planning of services is based upon the city unit and would be facilitated by knowledge of the homebound elderly in this area. However, generalizations of the needs of the homebound elderly in Calgary to those in smaller urban or rural areas must be made with caution.

It was the intention of this researcher to obtain a diverse and accurate representation of the homebound elderly in Calgary by allowing proxy responses. However, the study does not include a mental status questionnaire, nor are the responses specifically analyzed according to the degree of cognitive impairment. The only judgement the lay interviewers made with respect to respondents' cognitive abilities was whether the respondent required the assistance of a family member or friend to participate in the interview.

It is important to discuss the influence of sampling error and response error on the results of this study. These two types of systematic error are common to survey research and the conclusions drawn from this research must be weighed in light of these limitations. One potential source of sampling error was the method of sampling using agency lists. This method is incomplete, and probably causes the sample to be over-represented by people already using community support systems. The elderly whose families have assumed total responsibility for their care will have been missed. Relevant statistics for the sample were compared to available census data to ascertain the representativeness of the sample.

As well, most agency lists were confidential. An agency representative contacted the potential respondent to obtain permission to release his or her name and telephone number. Thus, the sampling frame missed those who would not allow the agency to release their names. Ineligibles on lists also affected response rates.

A source of response error is the tendancy of respondents to provide answers they feel are socially desirable. There is a concern that with the methodology employed, respondents' answers may have been influenced by the presence of a caregiver, and they may have minimized their needs. Social desirability remains a significant problem since it is extremely difficult to determine its extent.

Interviewer bias is a potential problem which should also be considered. An attempt was made to control this source of error through providing training sessions which focused on the importance of all interviewers maintaining an equal and accurate interpretation of the interview schedule and response categories. It is also possible that the sex of the interviewer may have had an influence on the responses given.

A final limitation of this study arises in the question of comprehensiveness. Interviewing the potential service user enhances the validity of a needs assessment. However, if providing respite is an important purpose of adult day care, it would be desirable to include a parallel survey of caregivers' needs. Unfortunately, this was beyond the scope and resources of this study.

Ethics

This study adhered to the following ethical guidelines in order to ensure that the rights of respondents and volunteers were not compromised.

1. Respondent's identities were kept anonymous by assigning each completed interview an interview number rather than recording the respondent's name.

2. Results were presented in compiled form. No individual results were presented which could identify a specific respondent.

3. Interviewers were carefully screened and trained to respect the rights and wishes of respondents.

4. A verbal consent procedure was performed by the interviewer before commencing the interview to ensure that the respondent was aware of the purpose of the study and his or her rights during the interview.

5. Client lists released by agencies were kept confidential. The data will be retained in coded form for secondary analyses in the future, subject to review by an ethics committee. Individual interview responses were destroyed once the data had been collected.

6. A summary report of the results of the study was distributed to the agencies involved, the volunteers, and any respondents requesting feedback.

7. There was a risk that the process of needs assessment would raise expectations for adult day care which cannot presently be met. Therefore, the volunteers, respondents, and caregivers were made aware that the results of this study would not necessarily lead to, or influence the development of, adult day care in Calgary.

CHAPTER 3

RESULTS AND DISCUSSION

A. RESULTS

Socio-demographic Characteristics of the Homebound Elderly

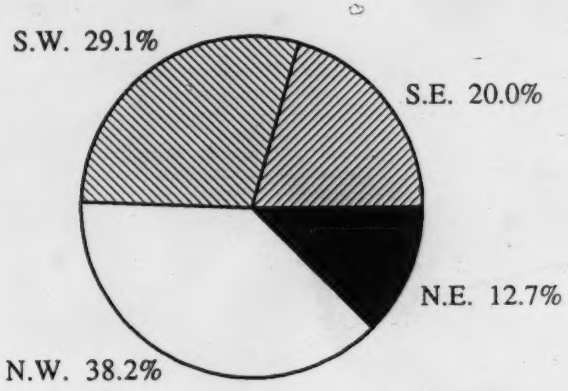
Great care was taken in this study to ensure that the sample obtained from the homebound elderly population in Calgary was as representative as possible. The sample was composed of 11 men and 44 women. 1988 census data shows that in Calgary 58.7 percent of the population age 65 and over are female. Therefore this sample is likely over- representative of females. The respondents ranged in age from 65 to 92 years of age, with 20 percent of respondents age 65 to 69, 21.8 percent age 70 to 74, 29.1 percent age 75 to 79, 21.8 percent age 80 to 84, and 7.3 percent 85 years of age or older (see table 1).

The geographical dispersion of respondents showed adequate representation from the four quadrants of the city. The largest percentage was living in the northwest (38.2 percent) and the smallest percentage was living in the northeast (12.7 percent) (see figure 1). The 1990 Calgary civic census indicates that the areas having the highest density of elderly people are the northwest (17.5 percent) and the areas surrounding the downtown core. Respondents lived in either single family or multi-family dwellings, or senior citizens' apartment buildings. As stipulated by the sampling criteria, none of the respondents were living in senior citizens' lodges or nursing homes.

Table 1. --Age of Respondents By Sex

Age	Males	Females	% of Total (N=55)
65-69	2	9	20.0
70-74	2	10	21.8
75-79	2	14	29.1
80-84	4	8	21.8
85+	1	3	7.3
Total	11	44	100.0

Figure 1. --Geographical Dispersion of Respondents



Analysis of the marital status of respondents revealed that 60 percent were widowed, 25.5 percent were married and the remaining were either divorced, separated or single. A significant difference was found between the marital status of men and women in the sample. The majority of male respondents were married (63.6 percent) whereas the majority of female respondents were widowed (68.2 percent) (see table 2). This trend is also apparent within the general population of the

elderly. In a report describing older Albertans (Alberta Senior Citizens Secretariat 1986) only 42 percent of females were married while 57 percent of females were widowed. Conversely, 75 percent of males were married. Even in the 85 and over age category, one third of males had a spouse. Statistics show that more single and widowed elderly people are institutionalized than are people who remain married in later life (Health and Welfare Canada 1982).

Table 2. --Marital Status by Respondents' Sex

Marital Status	Male (%)	Female (%)	% of Total (N=55)
widowed	27.3	68.2	60.0
married	63.6	15.9	25.5
divorced	0.0	9.1	7.3
single	0.0	6.8	5.5
separated	9.1	0.0	1.8
total	100.0	100.0	100.0

The education level of the sample coincided with the average education level of this age cohort. Aproximately 36 percent had primary school education or less, 23.6 percent had a high school diploma, and 10.9 percent had a university degree (see table 3). The majority of respondents reported that their income meets their needs adequately (50.9 percent) or very well (20.0 percent) (see table 4).

Table 3. --Respondents' Education Levels

Education Level	% of Total (N=55)
primary school	32.7
some high school	16.4
high school diploma	23.6
business/technical school	7.3
some university	5.5
university degree	10.9
no formal education	3.6

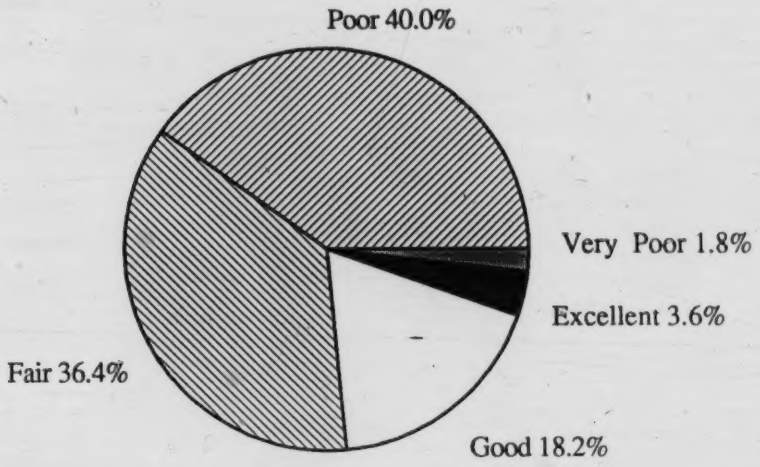
Table 4. --Respondents' Income Satisfaction

Income Satisfaction	% of Total (N=55)
very good	20.0
adequate	50.9
with some difficulty	20.0
not very good	7.3
totally inadequate	1.8

Health

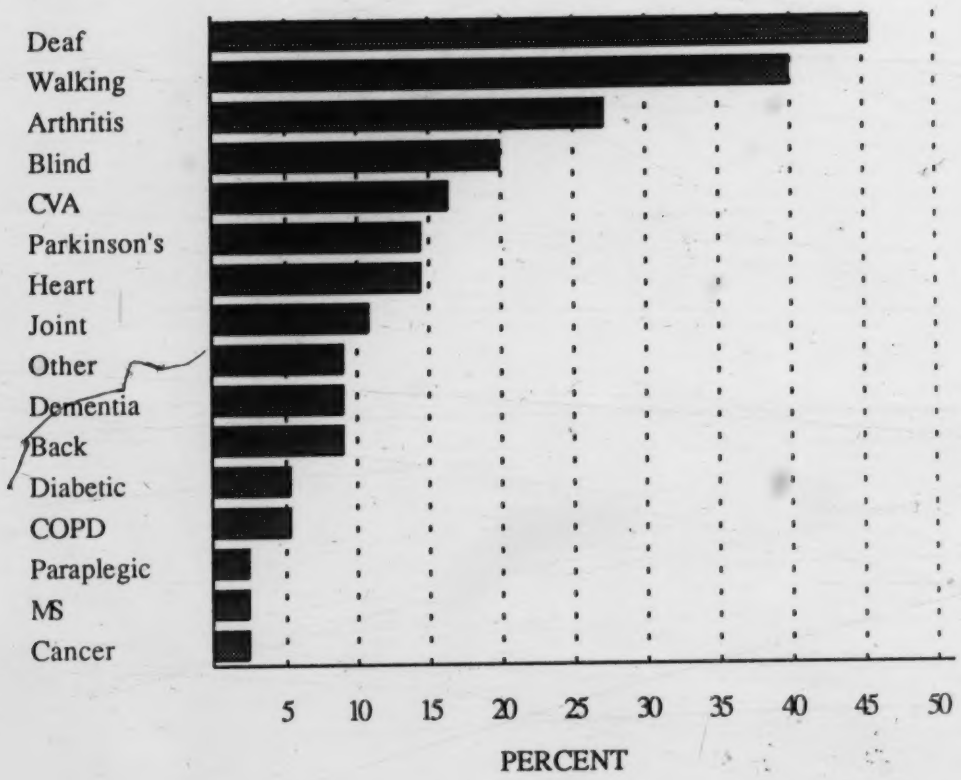
One of the stated purposes of this research project was to gain an understanding of the perceived health status of the homebound elderly in the community. Surprisingly, when asked how they perceived their health for someone their age, a number reported excellent (3.6 percent) or good (18.2 percent) health despite their disabilities. The majority, however, felt that they were in fair (36.4 percent), poor (40 percent) or very poor (1.8 percent) health (see figure 2).

Figure 2.--Respondents' Perceived Health



A more objective way of measuring health status is to record the occurence of specific disabilities. In this sample, 20 different types of disabilities were recorded. The mean number of chronic disablilities reported was 2.4. The most frequently reported chronic disability was hearing impairment (45.4 percent), followed by significant difficulty in walking (40 percent), arthritis (27.3 percent) and visual impairment (20 percent). However, chronic diseases common to older adults such as Parkinson's disease, multiple sclerosis, dementia, stroke, and heart disease were also well-represented (see figure 3).

Figure 3. --Proportion of Respondents Reporting Different Disabilities



During the interviews, questions were asked regarding the respondents' ability to perform physical and instrumental activities of daily living as an alternate measure of health status. The respondents' Activities of Daily Living Scale scores ranged from 0.64 to 1.93 on a scale of zero to two, where a low score indicates dependence. The mean score was 1.47. These scores were then analyzed to rate respondents as either mildly, moderately or severely impaired.[5] Mildly impaired respondents (18.2 percent of the sample) were able to make their own meals and re-

[5] Rating criteria from the Duke University Centre for the Study of Aging and Human Development (1978). Multidimensional Functional Assessment: The OARS Methodology, Durham, NC.

quired assistance in less than four activities of daily living. Moderately impaired respondents (65.5 percent of the sample) were dependent in at least four activities of daily living and regularly required help with meals. Severely impaired respondents (16.4 percent of the sample) were dependent on others in making meals and bathing and also had trouble getting to the bathroom on time (see figure 4). A statistically significant relationship was found to exist between perceived health and activities of living scores ($r=.68$, $p<.05$), confirming the construct validity of these measures of health status.

The term "homebound" is an appropriate label for this sample because 92 percent of respondents required assistance to leave their homes due to physical or mental impairments. The reported frequency with which respondents left their homes is set out in Figure 5.

This graph indicates that over one quarter of the sample went out less than once every two weeks. In the course of the interviews, many respondents expressed the view that the winter weather significantly curtailed their ability to go out since these conditions often make travel- ling even short distances unsafe for those relying on the assistance of others or adapted equipment.

Figure 4. --ADL Status of Respondents

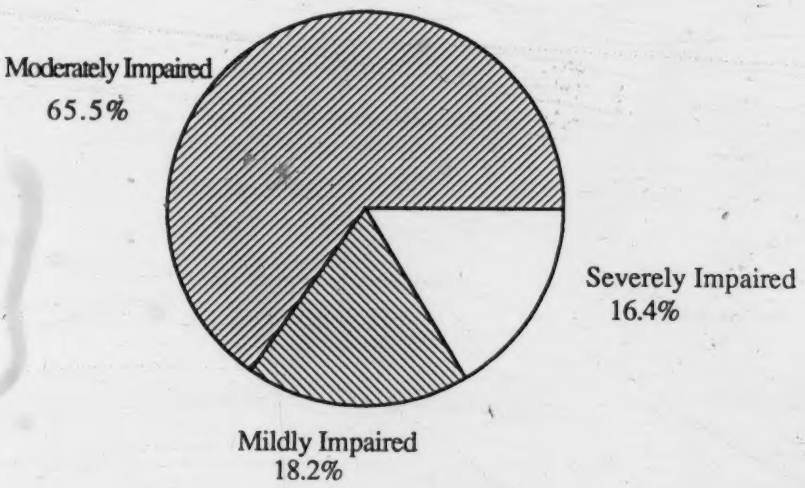
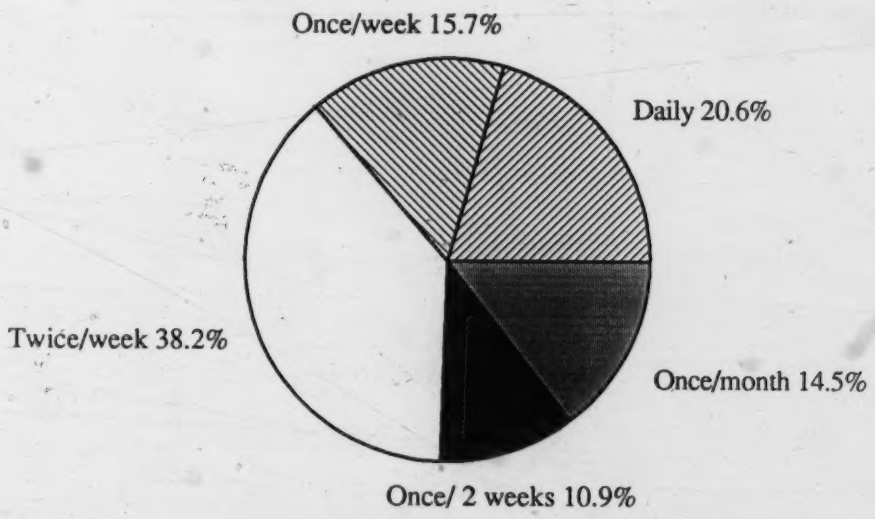


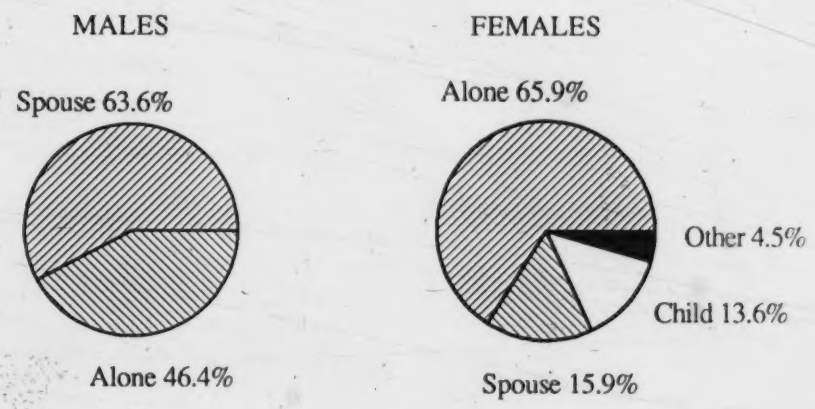
Figure 5. --How Often Respondents Leave their Homes



Social Support

McDaniels (1986) notes that, with the exception of a few specific ethnic groups, there has been a decline in multi-generational living arrangements within Canadian families. Consistent with this, the great majority of those interviewed in this study lived alone (60 percent) or with a spouse (25.5 percent). Only 11 percent of respondents lived with their adult children (see figure 6). Again, since a greater percentage of males in the sample were married than females, those living alone were predominantly older women.

Figure 6. --Living Arrangements By Respondents' Sex



The reported primary caregiver also reflected the respondent's marital status. Males most often reported their spouse was the primary caregiver whereas females reported that an adult child or a friend filled this role. It is interesting to note that 70 percent of the adult child caregivers were daughters and only 30 percent were sons. On average, the primary caregiver spent one to two hours per day or less

helping the subject. Generally, the homebound elderly respondents did not feel that they were a burden to their caregivers. However, those living with their children were more likely to feel a burden than those living alone (see table 5).

Table 5. --Major Caregivers by Respondents' Sex

Caregiver	Males	Females	% of Total (N=55)
son/daughter	2	21	41.8
spouse	7	7	25.5
friend	2	12	25.5
*other	0	4	7.2
total	11	44	100.0

*other includes sibling, housekeeper, other relative

To further describe the social support networks of the homebound elderly, the total number of helpers that respondents relied upon and the types of help provided were analyzed. The sample mean number of helpers was calculated to be 2.47. However, males averaged 2.91 helpers and females averaged 2.34 helpers. This discrepancy is likely explained by the fact that males tend to have a spouse within their social support network and females do not. Overall, the most frequently reported helpers (in addition to the primary caregiver) were friends, followed in order by sons, daughters, spouses, other relatives and volunteers (see table 6).

The types of help received by repondents varied widely. On average, subjects required assistance in three or four different areas (see table 7). Nearly 90 percent of the sample had family or friends willing to run errands for them. Practical, occasional support such as running errands and providing transportation tended to

be the areas in which respondents allowed friends to help. More regular health or personal care was most often provided by family members. Though not as commonly required, family members also tended to provide help with household maintenance and financial matters.

Table 6. --People Who Help Respondents

Helper	% of Total (N=55)
friend	72.7
son	52.7
daughter	47.3
other relative	27.3
volunteer	23.6
sibling	3.6
housekeeper	1.8

Mean total number of helpers=2.47 SD=1.07

Table 7. --Type of Help Received by Respondents

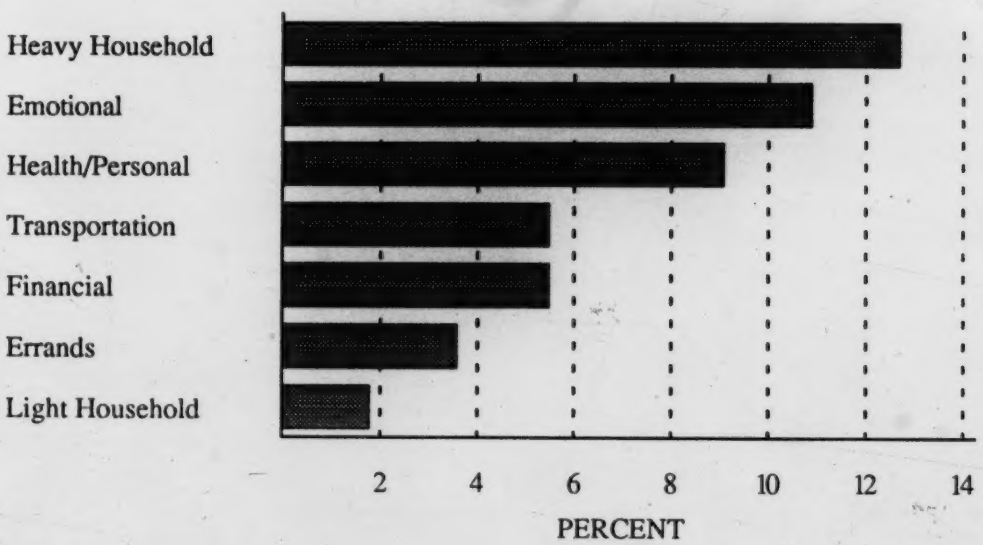
Type of Help	% of Total (N=55)
errands	89.1
emotional support	83.6
transportation	52.7
health/personal	47.3
financial	29.1
heavy household	25.5
light household	20.0

Mean total types of help=3.46 SD=1.41

Emotional support through visiting and telephoning was also received from family and friends by most respondents. Often, the practical help respondents required was minimal but necessary to maintain their residence in the community. However, emotional support was considered crucial assistance since the subjects' limited mobility restricted the number and variety of social contacts.

Only old age and a lack of social supports have consistently proven to be major predictors of institutionalization (Brock and O'Sullivan 1985; Shapiro and Tate 1988). Over one quarter of the homebound elderly in this study felt they were not receiving enough informal support to meet their needs. Interestingly enough, 42.8 percent of these respondents stated that they required more emotional support. Assistance with heavy household chores was also frequently cited as lacking, followed by assistance with health and personal care (see figure 7).

Figure 7. --Deficient Areas of Informal Support



In many cases, respondents without family members available to help depended on formal services to maintain themselves. Those with inadequate social support networks relied on up to seven different formal services to meet their needs. Generally, however, formal services were used to augment the efforts of family and friends. The sample mean number of formal services currently being used was 3.1. The four services most frequently accessed by the homebound elderly in this sample were a homemaker service (52.7 percent), a seniors' centre (45.5 percent), handibus or handitaxi (40 percent), and a church outreach program (27.3 percent) (see table 8). Few subjects relied on their informal support networks for assistance with chores such as housekeeping because this formal service is readily available and using it reduces their social dependence.

Table 8. --Formal Services Received by Respondents

Service	Used in Past (%)	Currently Using (%)
Meals on Wheels	29.1	5.5
Home Care	23.6	12.7
Homemaker Service	9.1	52.7
Shopping Service	1.8	16.4
Homebound Reader	1.8	5.5
Seniors Assisting Seniors	3.6	14.5
Public Health Nurse	32.7	25.5
Handibus/Handitaxi	14.5	40.0
Seniors' Centre	25.5	40.5
Day Hospital	12.7	1.8
Church outreach	7.3	27.3
Lifeline	0.0	7.3
CNIB	0.0	7.3
Parkinsons Society	0.0	12.7
Project Home Help	0.0	20.0
Other	1.8	18.2

Mean total of formal services currently using=3.13 SD=1.62

Leisure Lifestyles

Advanced age and chronic disabilities tend to restrict the leisure and social opportunities of the homebound elderly. It is clear that the environments of leisure are drawn into a tighter circle for this segment of the population (Kelly, Steinkamp and Kelly 1987). In order to further advance knowledge regarding the homebound elderly, this study attempted to describe the unique leisure lifestyles of this cohort.

Respondents were encouraged to list their leisure activities using their own definitions of the term. More than half of the sample reported engaging in at least five different activities. The most frequently reported activities were watching television, reading or listening to tapes, hobbies, attending community events, and visiting with others.

The day to day leisure environment for this group is necessarily the home environment. However, even within the home, leisure choices are limited by resource restrictions related to health, income, mobility, and physical ability.

In order to analyze the relative occurrence of home versus community activities, the reported leisure interests were divided into two categories. The "home leisure" category included activities which were generally passive and solitary while the "community leisure" category included activities which were active or involved social contact. Not surprisingly, respondents more frequently engaged in leisure in their homes than in the community. However, the mean number of community activites (2.3) was not much lower than the mean number of home activities (2.5) which respondents reported were part of their leisure lifestyles (see table 9).

Table 9. --Respondents' Leisure Activities

Home Leisure	% of Total (N=55)	Community Leisure	% of Total (N=55)
television	89.1	community event	54.5
read/tapes	69.1	visit	50.9
hobby	61.8	shopping	38.2
cooking	9.1	church	27.3
music	9.1	cards/game	21.8
pets	7.3	outing/drive	14.5
other	10.9	exercise	12.7
		dining out	7.3

This similarity in means masks the integral differences between these two types of leisure in the lives of the homebound elderly. The time spent in home leisure far outweighed the time spent in community leisure. This fact is true not only for the homebound elderly, but for the general population as well. For the average subject in this study, community leisure pursuits were engaged in less than once every two weeks. Yet, the community activities were often the most valued by respondents.

This study endeavored to discover the degree to which homebound elderly respondents found their leisure to be personally meaningful and rewarding. Most respondents (63.6 percent) reported they would like to be more active than they are presently. However, 67 percent of the sample felt that health problems prevented them from increasing their leisure involvement. This barrier is significant because it cannot be easily overcome or programmed away. The next most frequently mentioned barriers to leisure were lack of transportation and fatigue (see table 10). The

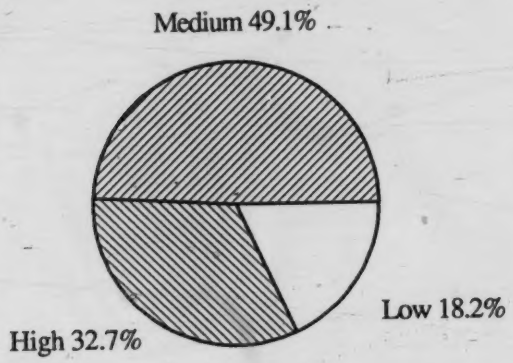
constraints reported by respondents were not isolated; they were interdependent and existed to varying degrees for different individuals.

Table 10. --Barriers to Leisure

Barrier	% of Total (N=55)
health	67.3
transportation	27.3
fatigue	23.6
no interest	16.4
safety	12.7
no partner	10.9
no time	10.9
money	7.3
other	1.8

The sample mean leisure satisfaction score was calculated to be 2.15 on a scale of one to three. The sample was then statistically clustered into high, medium and low leisure satisfaction groups. The results of this classification were that 32.7 percent of the sample rated high, 49.1 percent of the sample rated medium and 18.2 percent of the sample rated low on this index (see figure 8). In contrast, the *1989 Survey of Leisure Interests of Older Adults* (Calgary Parks and Recreation 1989) reported that 65 percent of the average senior population in Calgary was satisfied with their leisure. However, the results of these two studies cannot be directly compared because the instruments used to measure leisure satisfaction were not identical.

Figure 8. --Proportion of Respondents Reporting Different Levels of Leisure Satisfaction



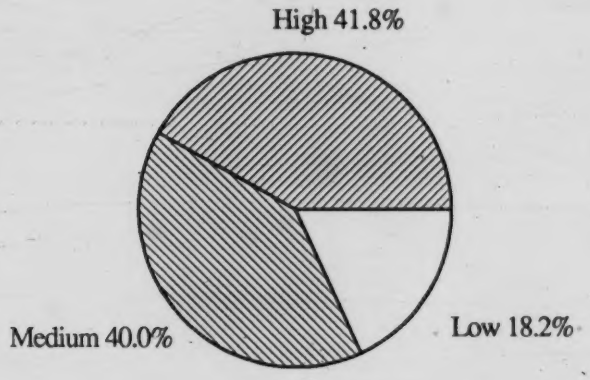
Morale

One research question of this study was whether leisure satisfaction and perceived health were related to quality of life in old age. In order to accurately assess the needs and situation of the homebound elderly, the morale or life satisfaction of this group must therefore be described.

The 17-item PGC Morale Scale (Lawton 1975) was implemented in the interview to measure the morale factor. Answers were rated as demonstrating poor or good morale on a scale of one to two. The sample mean morale scale score was 1.56. When indexed into three groups using the mean as a reference, 41.8 percent of respondents were rated high, 40 percent were rated medium and 18.2 percent were rated as demonstrating low morale (see figure 9).

A clear, positive relationship was established between leisure satisfaction and morale through cross-tabulation of the data (Chi Square(4,55)=20.3; $p<.001$). Though this analysis cannot indicate a causal relationship, it does demonstrate that these two factors are dependent.

Figure 9. --Proportion of Respondents Reporting Different Levels of Morale



As previously mentioned, the most significant barrier to leisure satisfaction was reported to be health problems. It would therefore seem logical that perceived health would show a positive relationship to leisure satisfaction and morale. Yet, no such relationship was found at a statistically significant level. However, leisure satisfaction did vary significantly with the activities of daily living status of respondents (Chi Square(4,55)=10.3; $p<.05$). Seventy percent of those only mildly impaired in their ability to perform instrumental and physical activities of daily living were satisfied with their leisure lifestyles.

Need for Adult Day Care

The research findings presented here describe the perceived needs of the homebound elderly and their reactions to the concept of adult day care services.

In the interview, six different needs were assessed which it was assumed would be ameliorated by an adult day care program. Nearly 62 percent of respondents expressed three or more of these six needs. It was discovered that the most

frequently reported need of respondents was to feel more useful and productive (69.1 percent). Other frequently reported needs were the need to go out more and the need to do more leisure activities (60.0 percent each). Over half of those interviewed felt they needed to meet new people and one quarter felt they needed to give their caregivers a break. Only 16.4 percent of respondents were concerned with receiving regular nursing care (see table 11).

When asked to rank these needs, respondents reported that the most immediate was "to get out of the house more", followed by "to increase leisure involvement", and "to feel more useful and productive". This ranking is interesting and important because it implies that the majority of respondents felt their quality of life would benefit from changes in their leisure environments and leisure lifestyles. Respondents, on average, felt adult day care could be a solution to their needs.

Table 11. -- Proportion of Respondents Reporting Different Needs

Need	% of Total (N=55)
feel useful	69.1
go out more often	60.0
leisure activity	60.0
meet new people	50.9
caregiver respite	25.5
more nursing care	16.4

Overall, the sample's impression of adult day care programs, based upon the description in the interview, was good (45.5 percent) to excellent (38.2 percent). A cautionary note regarding this result is that it was often discovered in later questioning that this response was based upon a general impression of the idea rather than an individual's perceived need for such a program (see table 12).

Respondents tended to have specific and definite impressions of what would be the positives and negatives of day programs. The reported positives again reflect the perceived needs of respondents. Many felt a day program would provide an opportunity to socialize, to do activities, and to get out of the house. That adult day care would provide a respite service was favourable to 29 percent of respondents and a few felt that the meal, security and health care were positive aspects (see table 13).

The reported negatives of adult day programs were more diverse than the reported positives. The most frequently stated negatives were that respondents were unsure and required more information, respondents felt their health problems would prevent participation in such a program, and the length of the program would not be appropriate for their needs. The fact that poor health is considered a barrier to participation by many respondents is a significant consideration for those developing adult day care services. Other respondents stated that they did not need such a program or the idea "wasn't for them". In explanation, some of these respondents said they preferred to be by themselves rather than in a group, especially a group with ill and old people, and some felt that the activities being offered would not appeal to

them. The method and cost of transportation were also viewed as negatives because most respondents assumed this service would not be provided (see table 13).

Table 12. --Respondents' Opinions About Adult Day Care

Rating Idea of Adult Day Care	% of Total (N=55)
excellent	38.2
good	45.5
fair	10.9
poor	1.8
don't know	3.6

Table 13. --Perceived Negatives and Positives of Adult Day Care

Positives	% of Total (N=55)	Negatives	% of Total (N=55)
socialize	43.6	need info	20.0
activity	40.0	poor health	18.2
go out	36.4	length	18.2
respite	29.1	transport	16.4
meal	14.5	don't need	16.4
security	12.7	ill/old people	14.5
health care	10.9	non-social	12.7
		fearful	9.1
		other	7.3

In this study, the need for adult day care was assessed from the point of view of the potential clients- the homebound elderly. A perceived need for adult day care index was calculated and effectively divided the sample into those who felt they ne-

eded adult day care (63.6 percent) and those who felt they did not need this program (36.4 percent).

In order to determine if any specific groups should be targetted for adult day care programs, this need index was crosstabulated with each socio-demographic variable. Only two such variables showed a significant relationship with a need for adult day care: frequency of leaving one's home (Chi Square(4,55)=11.8; $p<.01$) and perceived health status (Chi Square(2,55)=5.8; $p<.05$). The only other clear indicator of a need for day care was stating a need for respite care (Chi Square(1,55)=3.9; $p<.05$) . Notably, all five respondents or proxy reporting a dementia-type illness stated a need for a respite service day program.

Clearly, few specific target groups may be identified from this data. It appears that the homebound elderly population is quite diverse and has many different needs. It follows, then, that people requiring adult day care programs and their reasons for doing so are just as diverse.

Expectations of Adult Day Care

Analysis of respondents' feelings and expectations regarding the particulars of adult day care services produced the following results. Most respondents felt that a senior citizens' centre would be an appropriate setting for an adult day program (65.5 percent). None of the respondents wished the program to be located in a nursing home. Regardless of the setting, over 65 percent of respondents felt it was fairly important or very important that the location of the day program was close to their homes even if transportation was provided (see table 14).

Table 14. --Respondents' Preferred Location for Adult Day Care

Location	% of Total (N=55)
seniors' centre	65.5
school/community building	18.2
don't know	12.7
other	3.6
nursing home	0.0

In regards to the program itself, over 80 percent of respondents felt that transportation, a hot meal, entertainment and social opportunities were essential services to be offered in an adult day program. Sixty to 70 percent of the sample felt that health monitoring, trips to community events, cards and games, personal care, and health education were necessary. Forty to 59 percent of the sample requested counselling, volunteer opportunities, a rest period, arts and crafts, and exercise. In contrast, very few people interviewed required or wanted television or bible study activities, physiotherapy, bathing or assistance with dispensing medication (see table 15).

The four top-ranked services expected in an adult day program were transportation, a hot meal, entertainment and social opportunities. Clearly, leisure services were considered to be greater in priority for most respondents than health and personal care services.

Table 15. --Respondents' Service Expectations of Adult Day Care

Services Expected	% of Total (N=55)
transportation	92.7
entertainment	87.3
meal	81.8
social opportunities	81.8
health monitoring	69.1
outings	65.5
health education	65.5
personal care	65.5
cards/games	60.0
arts and crafts	56.4
rest period	50.9
volunteer opportunities	49.1
counselling	45.5
exercise	40.0
physiotherapy	38.2
bible study	25.5
television	23.6
bath	16.4
medication	9.1
other	5.5

B. DISCUSSION

The Health Factor

Health depends on many factors other than the absence of disability. For example, income security, social contacts, leisure, and satisfaction with one's standard of living all affect one's health (McDaniels 1986). It is apparent from the results of this study that the homebound elderly perceive their health to be a significant barrier to participation in both leisure activities and adult day care programs. Therefore, in examining the needs of the homebound elderly, it is essential that the implications of this barrier be addressed.

It has been suggested that the potential for growth and continuing engagement disappears when an elderly person becomes disabled. Cohen (1988,25) suggests:

> American ageism is focused upon the elderly with disabilities as opposed to the well elderly, and further, that the elderly themselves have concluded that when disability arrives, hope about continued growth and self-realization, and full participation in family and society must be abandoned so that all energy may be directed to avoiding the ultimate defeat, which is not death, but institutionalization, which is regarded as a living death.

The main thrust of Cohen's statement, and an observation of this study, is that health problems can become all-consuming for the aged individual. As health deteriorates so does perceived social competence. This directly influences leisure participation which in turn affects leisure satisfaction.

The chronically disabled respondents in this study demonstrated the fear of institutionalization alluded to in the above passage. Over 50 percent of respondents felt that Calgary nursing homes would be either moderately unpleasant or very unpleasant places in which to live. Furthermore, 80 percent reported that they would

like to delay a move into such a facility for as long as possible or that they would never want to go. These results indicate that the homebound elderly struggle to protect their independence and autonomy in the community.

In order to experience autonomy, an individual must regard the source of his or her action, or locus of control, as resting with himself or herself (Kuypers and Bengtson 1973). However, declining hearing and visual capacities, reduced financial independence and mobility, loss of parenthood or work role, and the onset of physical illness or impairment may contribute to feelings of helplessness and powerlessness in old age. In this "learned helplessness" state the frail elderly are unable to respond to or initiate action on their environment (Seligman 1975). Iso-Ahola (1980) states that if a person believes his or her helplessness is due to a personal inadequacy or incompetence, he or she will be more likely to generalize this reaction to many situations.

Respondents in this study who felt that health problems would prevent them from attending adult day care demonstrate this helpless state. They have generalized helplessness to situations which may actually improve their physical and mental health.

The Significance of Leisure

Leisure scholars have long agreed that leisure is a 'state of mind' and that the leisure experience has profound benefits which go beyond the mere benefits of activitiy. Studies have demonstrated that meaningful leisure is particularly important to the well-being of older adults. Iso-Ahola (1980) states that in leisure, older adults seek optimum arousal and incongruity from their environments. However, this op-

timizing process pre-supposes that the person has abilities and opportunities to exercise control over his or her environment. This is not always so, especially in the case of frail elderly individuals. For example, the frail elderly respondents in this study expressed the need to go out more often and to participate in more leisure activities, yet their health status was a significant barrier to doing so. Their leisure lifestyles were, therefore, substantially dictacted by the personal and social resources available to them.

If leisure, then, is an index of respondents' abilities and resources, the intensity and meaning of their leisure is central to their current roles and identities (Kelly 1990). In this study, leisure satisfaction was measured to assess these dimensions of meaning. It is difficult to separate cause and effect among the concepts of health, morale and leisure satisfaction. Yet, the results of this study corroborate the prevailing thought in the literature that leisure satisfaction positively influences life satisfaction. The feedback people receive from engaging in leisure activities may include feelings of mastery, pleasure, accomplishment, choice and efficacy. It follows that meaningful leisure would contribute to one's sense of autonomy and control which would, in turn, positively influence one's morale. Since most health problems in old age are chronic and irreversible, the potential for improving quality of life centres on experiencing and enhancing these feelings.

Thus, the evidence suggests that morale-improving, client-centred leisure services must take precedence in an adult day care program. By orienting the client in the direction of personal control, at least in recreational activities, one hopes to create an expectation of personal causation. This leads the client to believe in ef-

fectual personal responses, causes the client to perceive that he or she still has the freedom to choose despite the constraints imposed by illness, and ultimately extinguishes the learned helplessness reaction (Mobily 1985). Generally termed "therapeutic recreation", the aim of these services is to strengthen personality aspects of clients which are not affected by chronic disability.

Social Support Networks

There is no simple formula to explain the aging process or to guarantee healthy adjustment to aging. Aging is a biological fact, and while it involves some personal psychological adjustment, it is also very much a social process.

With the proportion of elderly in the population increasing as mortality and fertility rates decrease, dependency becomes a social and economic problem as well as an individual concern. One must therefore consider that social structural changes to promote autonomy and independence can have a powerful influence on the health and well-being of the homebound elderly. One such change would be the addition of adult day care programs to the community services network.

Conclusive evidence exists that the elderly expect help from their families; yet most older persons also desire to remain independent of their children for as long as possible (Quinn 1984). Consistent with these observations, this study found that the majority of respondents in the sample lived alone and had developed functional family and community support networks to meet their needs. The importance of friends to the homebound elderly was also revealed by the results of this study. Nearly 73 percent of respondents had at least one friend who was part of their social support network. Kuypers and Benngtson (1973) state that by having several or

even a single close friend with whom they can share their thoughts, fears and interests, older people are protected from many of the ageist definitions imposed by the society at large, and are more resistant to social dependency.

Clearly, the homebound elderly look to friends for emotional support. Yet the loss of friends, due to death, relocation or institutionalization, is prevalent in the oldest age categories. At the same time, opportunities to meet new people are few because disabilities and attitudinal barriers restrict social outings. A deficit in emotional support was stated by respondents of this study to be the greatest contributing factor to an inadequate social support system. It is then perhaps not surprising that over half the respondents felt the need to meet new people and regarded adult day care as one way to expand their circle of friends. Friendships among clients in adult day care centres are potentially valuable because, ideally, there is a mutual exchange of support and encouragement to continue living independently.

In addition to receiving help from family and friends, most respondents in this study had accessed one or more of the formal services available to the homebound elderly in the community. However, they often reported that formal services were too limited or inflexible to comprehensively meet their needs.

Data show that older persons and their caregivers make greater use of formal services as the level of disability increases. Mutschler and Callahan (1990) found that the frail elderly more easily accessed supportive services that were linked to commonly utilized medical services. Therefore, though it is important to maintain the autonomy of supportive services such as adult day care, establishing connections

and a referral process with the medical community is essential in order to reach the target population.

Assessing the Need for Adult Day Care

Target Groups:

The literature identified target groups for adult day care as those at risk of institutionalization (Interdepartmental Committee on Long Term Care 1987). The results of this study provide additional, more specific information regarding target groups. These results indicate that though there is considerable variability in the home bound elderly who perceive a need for adult day care, the following three factors were found to be instructive for identifying potential target groups for adult day care services.

The first factor to be examined is the need for respite care. Respondents, or their proxy, who identified a need for such care obviously felt a strain on their social support systems. These respondents were generally those who were moderately to severely impaired in their daily activities and frequently required the assistance of others. As well, respondents with dementia-type disorders emerged from the data as a specific group requiring respite care. These respondents must be constantly supervised which often strains social relationships. If the purpose of adult day care is to compliment and maximize the use of informal and community service providers, a major target group should be those whose social support systems are perceived to be overburdened or dysfunctional.

The second factor to be examined is the frequency respondents leave their homes or, in other words, the extent to which they are homebound. One would ex-

pect a direct correlation between being homebound and needing adult day care; that is, the more homebound a subject the more likely that he or she would perceive a need for adult day care. However, exactly the opposite relationship was found. The least homebound respondents were significantly more likely to report a need for adult day care than the most homebound respondents.

The most plausible explanation for this apparent paradox is that the most homebound segment of the population has the highest dependency level and is therefore the most vulnerable to the state of learned helplessness and loss of autonomy discussed earlier. These people would be least open to changes in their routine or environment, regardless of whether they may be the most in need of such changes.

The third factor to be examined is perceived health status. As has been noted, health status is a precursor to the extent to which one is homebound. Therefore, these two factors are intertwined with a need for adult day care. The largest group of respondents who reported a need for adult day care perceived their health status to be poor. Yet, proportionately, those who reported good health were even more likely to feel a need for adult day care. This finding can be explained on the basis that those reporting good health are often the most mobile and independent. Feeling that they have control in both familiar and new situations, relative to those in poor health, they would be the most willing to try a new service. Conversely, many of those reporting poor health perceived their health to be a barrier to changing their routine and accessing adult day care services.

Not to be overlooked is the fact that 37 percent of respondents did not indicate a need for adult day care programs. These homebound elderly people were either coping well in the community or felt that adult day care was not an appropriate service for them. Therefore, adult day care should not be viewed as a panacea for the needs of all homebound elderly people.

Location:

It was important to respondents in this study that adult day care programs be part of their local communities rather than institutionally based. This result corresponds with previous studies which demonstrate that the disabled elderly have a fear of institutionalization and would naturally avoid any program connected with such facilities (Tobin and Lieberman 1976).

Services:

The unmet needs expressed by respondents identify gaps in their formal and informal support systems. Adult day care services should be offered which augment clients' support networks and target their expressed needs, such as that need expressed by the subjects of this study "to feel more useful and productive". Client choice and input into service decisions are therefore paramount.

In this study, leisure services were found to be higher in priority than health or personal care services. Despite this fact, over 60 percent of the sample requested that preventative health services such as health monitoring, health education and personal care be a component of the program. It appears that the homebound elderly require these health services to support or enhance their leisure participation.

These findings call into question the standards proposed by Alberta Health (1990) which stated that health monitoring, health education and transportation are optional services in an adult day care program. Transportation in particular was considered to be an essential service by the majority of respondents. A review of adult day care standards, incorporating this input from potential clients, is therefore indicated.

CHAPTER 4

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

A. SUMMARY

Purpose

Estimates of the need for adult day care have generally been based upon the opinions of professionals. The purpose of this study was to investigate the need for adult day care services in Calgary from the point of view of the homebound elderly people living in the community. A secondary purpose was to investigate the relationship between health, morale and leisure satisfaction in the lives of these homebound elderly people.

Method

The homebound elderly subjects were contacted through community agencies serving this population. Client lists were screened for those who were aged 65 or older and had one or more chronic disabilities causing them to be substantially homebound. A random sample was taken of a composite of the agencies' eligible client lists. The response rate of subjects who were telephoned was 59.1 percent.

In-person interviews were conducted with the respondents by older adult volunteers. Topics covered in the interview included: socio-demographic characteristics, activities of daily living, caregivers, leisure, morale, perceived need for adult day care, and expectations of adult day care. The OARS Instrumental and Physical Activities of Daily Living Scale (Duke University Centre 1978) and the Revised Philadelphia Geriatric Centre Morale Scale (Lawton 1975) were used to measure functional health status and morale respectively. To measure leisure satisfaction, a

nine item index was created from variables which explored respondents feelings about their home and community leisure and whether they found their leisure to be interesting and rewarding.

The interview schedule incorporated both open and closed response categories and allowed for proxy responses. A total of fifty-five interviews were completed, lasting an average of 66 minutes in length.

Results

Socio-demographic Characteristics: The sample was composed of 55 people (44 women and 11 men) ranging in age from 65 to 92 years. All four quadrants of the city were represented in this sample, with the highest proportion of respondents living in the northwest. Analysis of the marital status of respondents revealed that most female respondents were widowed whereas male respondents tended to be married. Overall, 60 percent of the sample was widowed. The majority of those interviewed felt that their incomes adequately met their needs. Thirty-six percent of the sample reported a primary school education or less. The demographics of this sample were found to correspond with available census data for this age group.

Health: The term "homebound" is an appropriate label for this sample because 92 percent of respondents required assistance, due to physical and/or mental impairments, to leave their homes. The majority of respondents reported that they were in fair (36.4 percent) or poor (40 percent) health. The mean number of chronic disabilities reported was 2.4. The most frequently reported disability was hearing impairment, followed respectively by significant difficulty in walking,

arthritis, and visual impairment. In total, over 20 different disabilities were recorded.

The functional health status of respondents, measured by the activities of daily living scale, was determined to be significantly correlated to respondents' perceived health ($r=.68$; $p<.05$). Over 18 percent were mildly impaired, 65.5 percent were moderately impaired and 16.4 percent were severely impaired in performing activities of daily living.

Social Support: Among the respondents in this study, 60 percent lived alone, 25.5 percent lived with a spouse and 11 percent lived with an adult child. Those living alone were predominantly older women. For males, the primary caregiver was most often a spouse whereas for females the primary caregiver was most often an adult child or a friend. On average, primary caregivers spent one to two hours per day caring for the respondents. The respondents generally reported that they did not consider themselves to be a burden to their caregivers.

The results showed that the mean number of helpers in the respondents' informal support networks was 2.5. The types of informal support received by respondents, in order of frequency, included: running errands, emotional support, transportation, health/personal care, financial support and household maintenance. The average respondent received informal help in more than three different areas. Yet, over one quarter of respondents felt that they were not receiving enough informal support to meet their needs. These respondents most often perceived a deficit in the area of emotional support.

Formal services were accessed to augment the efforts of family and friends. The mean number of formal services respondents were currently using was 3.1. The most frequently used service was a homemaker service. Formal services were often reported as being too limited or inflexible to comprehensively meet respondents' needs.

Leisure Lifestyles: The leisure lifestyles of the respondents in this sample were primarily restricted to the home environment. The activities chosen were substantially dictated by the personal and social resources available to each person. More than half those interviewed reported engaging in at least five different leisure activities. The most frequently reported activities were watching television, reading, engaging in hobbies, attending community events and visiting with others.

Over 60 percent of respondents wanted to be more active in leisure. However, 67.3 percent of respondents considered poor health to be the greatest barrier to doing so. Over 18 percent of the sample rated low on the leisure satisfaction index. In comparison, only 7.1 percent of the general seniors population reported being dissatisfied with their leisure lifestyles (Calgary Parks and Recreation 1989).

Need for Adult Day Care: Six needs were assessed which would predict a need for adult day care. When asked to rank these needs, respondents reported that the most immediate was "to get out of the house more", followed by "to increase leisure involvement", "to feel more useful and productive", and "to meet new people". Less imediate were the needs "to give one's caregiver a break" and "to receive

regular nursing care". Analysis of the index of need for adult day care showed that over 63 percent of respondents perceived a need for this service.

Most respondents were positive about the idea of adult day care. However, some negative comments included: that health problems would prevent participation, that the program length or content would not be appropriate, and that transportation would be a problem.

Three variables were found to correlate with a need for adult day care: perceived health status, degree to which a subject was homebound, and perceived need for respite care. Analysis of these results indicated that moderately impaired elderly people and/or those stating a respite need should be targetted for adult day care services.

Expectations of Adult Day Care: It was important to the subjects of this study that a day program be close to their homes. The majority of respondents reported that a seniors' centre would be the most appropriate location for an adult day care program. None of the respondents wished the program to be located in a long-term care facility.

The top four ranked services expected in an adult day care program were: transportation, a hot meal, entertainment and social opportunities. It was discovered that leisure services were higher in priority than health care services for the majority of respondents. However, many stated that they required ancillary health care services to support or enhance their participation in the leisure program.

Relationship Between Perceived Health, Morale and Leisure Satisfaction:

Crosstabulation of the results of this study showed that perceived health was not correlated with either leisure satisfaction or morale. However, a significant positive relationship was discovered between the leisure satisfaction and the morale of the homebound elderly respondents (Chi Square(4,55)=20.3: $p<.001$). Meaningful leisure is proposed to contribute to one's sense of autonomy and control, which, in turn, influences one's morale. Since most health problems in old age are chronic and irreversible, the potential for improving quality of life centres upon experiencing and enhancing these feelings of self-determination.

B. CONCLUSIONS

Canada's health care system is premised to a large extent on the medical model, and as such, acute illnesses and interventionist solutions tend to receive the most attention (McDaniels 1986). A concern of many is that as Canada's population ages, health care costs will become prohibitive. Yet, these rising costs could be offset by resource-saving policy changes in the delivery of health care to the elderly. As McDaniels (1986,80) points out "Many of the health policy issues raised by the acceleration of population aging are not problems of an aging society but problems of the health care system itself, which are exacerbated by population aging".

It has been stated previously in this discussion that illness and disability can breed vulnerability to loss of control and independence. Changes in the health care delivery system which promote the autonomy of the homebound elderly are therefore necessary. This study has assessed the need for the addition of adult day care programs into the continuum of care for the elderly.

The results of this assessment indicate that 63.6 percent of the homebound elderly population perceive a need for adult day care services. Taking this into consideration, along with the proportion of homebound seniors in the overall senior population, leads to the projection that the user rate is potentially 4.6 percent of the total senior population. The evidence suggests that those clients most likely to access adult day care would be those who are moderately functionally impaired and/or those who perceive a need for respite care.

Much attention has been focused upon developing new service delivery models for the care of the elderly in the community. Yet, it is essential that the current

system is further evaluated and its merits assessed before extensive investments are made in changes. Researchers must also consider the experiences of other countries with significant older populations. In Sweden, informal care is still the largest source of support for elderly people despite the fact that 80 percent of women ages 16 to 64 are in the labour market and a highly developed system of community and home-based services is provided by local governments (Hokenstaad and Johansson 1990). Obviously, the informal support network functions beyond that of mere service provision. It provides opportunities for reaffirmation of roles and relationships important to both the caregiver and care recipient. The goal, then, is to develop a plan whereby the formal service providers supplement rather than supplant the care and assistance available from the older person's informal support network.

Respondents in this study perceived adult day care to be valuable in that it extended the merits of their own informal support systems. They expressed their preference that an adult day care program should facilitate contact with peers and provide meaningful leisure opportunities within a safe environment. That the projected user rate calculated from the results of this study is higher than the rate actually observed in Manitoba and British Columbia is likely due to the fact that respondents were envisioning an adult day care service which would meet their individual needs.

The main theme of the following recommendations is that the system of adult day care must be dynamic and client- focused. It must encourage professionals, families and clients to expect improvements and renewed independence as well as continued dependence. Changes in status must be recognized and accompanied by

changes in services (Muschuler and Callahan 1990). Future research should evaluate the extent to which current adult day care services are meeting the needs and expectations revealed in this study.

C. RECOMMENDATIONS

1) Adult day care programs should target homebound elderly people in the community who state a need for respite care.

2) Adult day care programs might be most successfully targetted to moderately impaired homebound people who perceive their health status to be fair to good.

3) Further efforts should be undertaken to ensure that the more severly impaired homebound elderly are made aware of the available services and the benefits of these programs.

4) Adult day care programs should provide opportunities for clients to engage in personally rewarding and meaningful leisure.

5) Adult day care programs should provide opportunities for peer group support and social interaction.

6) Therapeutic recreation services should be employed in adult day care programs to enhance clients' leisure satisfaction.

7) Adult day care programs should maximize and compliment other formal services currently available to the homebound elderly.

8) Adult day care services should be as flexible as possible to meet individual client needs.

9) Services most requested in adult day care programs include: a hot meal, transportation, entertainment, social opportunities, health monitoring, health education, community outings, cards and games, and personal care services.[6]

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[6] These services were expected by at least 60 percent of the respondents.

Less frequently requested services in adult day care programs include: counselling, volunteer opportunities, rest periods, arts and crafts, exercise, physiotherapy, bathing and assistance with medications.[7]

10) Transportation should be provided or arranged by the adult day care program. Client travelling time to the program should be 20 minutes or less.

11) Adult day care programs should be located in senior citizens centres or other community buildings.

12) The adult day care referral process should be facilitated by the medical community.

13) Continuing research should be conducted into the value of alternative long term care services in the community.

Implications

These recommendations have implications for future planning of education programs, adult day care service delivery, and research. First, in order to facilitate recommendations four, five and six, therapeutic recreation specialists must be employed to oversee the direction of adult day care programming. The post secondary education system must therefore provide a course of study in therapeutic recreation which covers the assessment and treatment of the leisure needs of the disabled elderly. At this point, the only fully developed therapeutic recreation program is available at Mount Royal College in Calgary.

Second, all of these recommendations require flexibility on the part of adult day care providers. The essential services expected are expensive. Establishing a

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[7] These services were expected by less than 60 percent of respondents. The neccessity of these services is determined by the needs of the particular client group.

client-focused adult day care program will entail significant or creative budgeting and staffing as well as networking with other service providers.

Finally, these recommendations imply that it is essential that future research compare actual utilization rates of adult day care programs in Calgary with the results of this initial needs assessment. It would also be valuable to conduct a longitudinal study to assess the impact of adult day care programs on clients' leisure satisfaction and quality of life.

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APPENDIX A

ELIGIBILITY CRITERIA (TELEPHONE SCREENING)

* This study is being conducted by a Master's Student at the University of Alberta
* You were referred to us by _____
* We would like to interview you at your convenience
* All of the information gathered during the interview will be kept strictly confidential
* The types of questions that will be asked will include: questions about yourself; questions about the assistance you receive from others; questions about your leisure time; and questions about a new community program which will be described to you

* Are you interested in participating in an interview?

1 Yes
2 No

In this study we are focusing on people in similar circumstances. Therefore, I'd like to ask you a few quick questions before we set up an interview date.

1. Are you [illegible] years of age or older?

   1 Yes
   2 No (IF NO GO TO Q.7)

2. Do you have any chronic (permanent) disabilities?

   1 Yes
   2 No (IF NO GO TO Q.7)

3. If yes, Please name these disabilities.

   _____
   _____
   _____

4. When you leave your home, do you generally have to have someone accompany you?

   1 Yes
   2 No

5. Please indicate the response which best describes your ability to go places which are out of walking distance:

   1 Without help (can travel on bus, taxi)
   2 With some help (need somebody to accompany or help when travelling)
   3 Or are you completely unable to travel unless arrangements are made for a specialized vehicle like Handibus

6. INTERVIEWER: CONTINUE IF AT LEAST ONE OF THE FOLLOWING STATEMENTS IS TRUE:

   1 He/She has answered Yes to Q.4
   2 He/She has answered "with some help", or "completely unable" to Q.5

   IF ALL STATEMENTS FALSE GO TO Q.7

   IF AT LEAST ONE STATEMENT IS TRUE, SET UP AN INTERVIEW APPOINTMENT IN THE RESPONDENT'S HOME. RECORD:

   INTERVIEW NUMBER _____

   NAME OF RESPONDENT _____

   ADDRESS _____ PHONE _____

   DATE OF INTERVIEW _____

   TIME OF INTERVIEW _____

   The interview will be conducted by a volunteer (name) who is an older adult.

7. INTERVIEWER TERMINATE INTERVIEW
   EXPLAIN WHY RESPONDENT IS NOT ELIGIBLE
   THANK RESPONDENT FOR WILLINGNESS TO PARTICIPATE

APPENDIX B

VERBAL CONSENT PROCEDURE

Barbara Wilson is a Graduate Student at the University of Alberta seeking to assess the needs of homebound elderly people in Calgary. We would be pleased if you would help with the study by agreeing to participate in an interview in your home. Before you give your consent, it is important that you consider the following points:

1. You will be asked questions concerning your situation, your needs and your feelings and expectations regarding adult day programs.
2. Your participation in the study is voluntary and you may withhold answers to any questions.
3. Any information collected for this study will be treated confidentially and also anonymously through the use of code numbers.
4. Neither your name (or your caregiver's) will appear in any research report.
5. You may not directly benefit from participating in this study. However, hopefully this study will provide information which will be of potential value to those planning future services for seniors.

Do you have any questions?
Have your questions been answered to your satisfaction?

Do you understand these points and agree to participate in an interview?
(INTERVIEWER CIRCLE ONE)

1 Yes
2 No

IF YES, PROCEED WITH INTERVIEW SCHEDULE
IF NO, GO TO PART VII

APPENDIX C

INTERVIEW SCHEDULE: ASSESSING THE NEED FOR ADULT DAY PROGRAMS

DETERMINE WHETHER RESPONDENT WANTS OR NEEDS A PROXY PRESENT DURING THE INTERVIEW. TRY TO HAVE THE RESPONDENT ANSWER THE QUESTIONS DIRECTLY AS OFTEN AS POSSIBLE. IF PROXY MUST ANSWER, RECORD A "P" BESIDE THAT QUESTION NUMBER. IF THE INTERVIEW MUST BE TERMINATED FOR ANY REASON, GO TO PART VII.

PART IA: PERSONAL CHARACTERISTICS OF RESPONDENT

These first few questions deal with your personal characteristics.

1. How old are you?

   _____

2. Indicate respondent's sex:

   1 Male
   2 Female

3. What is your present marital status?

   1 Single
   2 Divorced
   3 Widowed
   4 Separated
   5 Married

4. What is the highest level of education you attained?[8]

   1 Primary school
   2 Some high school
   3 High school diploma
   4 Technical or business school diploma
   5 Some university or college
   6 University degree
   7 No formal education
   8 No answer

---

[8] Questions from: Research and Planning Unit, Family and Community Support Services, *A Profile of the Elderly in Calgary*, (Calgary, Alberta: The City of Calgary, 1983). Appendix.

5. How well do you think your income and assets (including that of your spouse where applicable) currently satisfy your needs?

1 Very well
2 Adequately
3 With some difficulty
4 Not very well
5 Totally inadequate

6. For your age, would you say your health is*...

1 Excellent (never prevents activities)
2 Good for your age (rarely prevents activities)
3 Fair for your age (occassionally prevents some activities)
4 Poor for your age (often prevents many activities)
5 Very poor for your age (health troubles or infirmity consistently prevents most activities

Comments? _____
_____
_____

7. _____ CHECK SPACE IF OBVIOUS HEARING IMPAIRMENT

PART IB: INSTRUMENTAL AND PHYSICAL ADL STATUS[9]

Now I'd like to ask you about some of the activities of daily living, things we all need to do as part of our daily lives. I would like to know how well you can do the following:

1. Can you use the telephone ...

1 Without help, including looking up numbers and dialing
2 With some help (can answer phone or dial operator in an emergency but needs a special phone or help generally)
3 Or are you completely unable to use the telephone

2. Can you go shopping for groceries or clothes (assuming you have the transportation) ...

1 Without help
2 With some help
3 Or are you completely unable to do any shopping

---

[9] ADL Scale from the Duke University Centre for the Study of Aging and Human Development (1978). *Multidimensional Functional Assessment: The OARS Methodology*, Durham, NC.

3. Can you prepare your own meals ...

1 Without help
2 With some help
3 Or are you completely unable to prepare meals

4. Can you do housework ...

1 Without help (heavy and light)
2 With some help (light)
3 Or are you completely unable to do any housework

5. Can you take your own medicine ...

1 Without help (in the right doses at the right time)
2 With some help (need help preparing or need to be reminded)
3 Or are you completely unable to take medicine on your own

6. Can you handle your own money ...

1 Without help (write cheques, pay bills, etc.)
2 With some help (can manage day to day buying but need help managing chequebook and paying bills)
3 Or are you completely unable to handle your money

7. Can you eat ...

1 Without help (able to feed self completely)
2 With some help (need help cutting food, etc.)
3 Or are you completely unable to feed yourself

8. Can you dress and undress ...

1 Without help (able to pick out clothes, dress and undress)
2 With some help
3 Or are you completely unable to dress and undress yourself

9. Can you take care of your own appearance, for example comb your hair, shave ...

1 Without help
2 With some help
3 Or are you completely unable to maintain your own appearance

10. Can you walk ...

1 Without help (except from a cane)
2 With some help from a person
3 Or are you completely unable to walk

11. Can you get in and out of bed ...

1 Without any help or aids
2 With some help (from a person)
3 Or are you totally dependent on someone else to lift you

12. Can you take a bath or shower ...

1 Without help
2 With some help (need help getting in and out of tub or need special attachments on the tub)
3 Or are you completely unable to bathe yourself

13. Do you have trouble getting to the bathroom on time?

1 Yes
2 No
3 Has catheter or colostomy

PART II: CAREGIVERS

These questions deal with the formal and informal help you receive from others.

1. With whom do you currently live?

1 Alone
2 Spouse
3 Child - Son(s)
4 Child - Daughter(s)
5 Sibling
6 Other relative, Please specify _____
7 Friend

2. Who is the person who helps the most with your day to day care? (not an agency)

1 Spouse
2 Child - Son
3 Child - Daughter
4 Sibling
5 Other relative, Please specify _____
6 Friend

3. How much time during a typical day does this person spend on your care?

1 Less than 1 hour
2 1 to 2 hours
3 3 to 4 hours
4 5 hours or more

4. Do you ever feel that you are a burden to this person?

1 Often
2 Sometimes
3 Rarely
4 Never

5. Who are the people who help you informally? (that is, friends and family, not an agency). PROBE FOR TYPES OF HELP INCLUDING: HEALTH RELATED, HOUSEHOLD, FINANCIAL, TRANSPORTATION, ERRANDS, EMOTIONAL SUPPORT.

Helper	Type of Help	Frequency		
		2-3 times/ wk or more	once/wk to once/2 wks	once a month
_____		1	2	3
_____		1	2	3
_____		1	2	3
_____		1	2	3
_____		1	2	3
_____		1	2	3

6. Is the informal support you are currently receiving enough to meet your needs?

1 Yes Please comment_____
2 No _____
3 Don't Know _____

7. Is there any type of help you would like more of?

_____

_____

8. Now I would like to know if you have used or are currently using any of the following services for seniors* ...

	Never Used	Have Used In Past	Currently Using
1 Meals on Wheels	1	2	3
2 Co-ordianted Home Care			
3 Homemaker Service			
4 Shopping Service			
5 Homebound Reader Service			
6 Seniors Assisting Seniors			
7 Public Health Nursing			
8 Handibus			
9 Senior Citizens Centre			
10 Day Hospital			
11 Church Outreach Program			
12 Others, Please Specify			

_____

_____

PART III: LEISURE

Now I'd like to ask you some questions about what you like doing in your spare time.

1. What leisure and recreational activities do you currently participate in? AFTER EACH RESPONSE ASK "HOW OFTEN"

Activity	Frequency		
	2-3 times/ wk or more	once/wk - once/2 wks	once a month
_____	1	2	3
_____	1	2	3
_____	1	2	3
_____	1	2	3
_____	1	2	3

2. Would you like to be more active in your spare time than you are presently?

1 Yes
2 No
3 Don't Know

3. What is stopping you from being more involved in leisure activities? (i.e. money, time, transportation, partner ...)

_____

_____

_____

4. Do you feel bored often, sometimes, rarely, or never?

1 Often
2 Sometimes
3 Rarely
4 Never

5. Would you say that the time you spend in the following activities is too much, too little, or about right?

	too much	too little	about right
1 Visiting with others	1	2	3
2 Watching TV/Radio			
3 Reading			
4 Sleeping			
5 Alone			

6. Are your spare time activities interesting to you?

1 Almost always
2 Sometimes
3 Almost never
4 Don't Know

7. Do your leisure activities give you a sense of accomplishment?

1 Almost always
2 Sometimes
3 Almost never
4 Don't Know

PART 1V: MORALE

These next questions are more personal. As I read each statement, please answer yes or no according to whether you feel the statement applies to you or not.[10]

1. Little things bother me more this year.

   1 Yes
   2 No
   3 Don't Know

2. I sometimes worry so much that I can't sleep.

   1 Yes
   2 No
   3 Don't Know

3. I am afraid of a lot of things.

   1 Yes
   2 No
   3 Don't Know

4. I get mad more easily than I used to.

   1 Yes
   2 No
   3 Don't Know

5. I take things hard

   1 Yes
   2 No
   3 Don't Know

6. I get upset easily.

   1 Yes
   2 No
   3 Don't Know

---

10 These items are taken from: Lawton, M.P., "The PGC Morale Scale- A Revision," *Journal of Gerontology, 30* (1075): 85-89.

7. Things keep getting worse as I grow older.

1 Yes
2 No
3 Don't Know

8. I have as much pep as I had last year.

1 Yes
2 No
3 Don't Know

9. As you get older you are less useful.

1 Yes
2 No
3 Don't Know

10. As I get older things are better/worse than I thought they would be.

1 Better
2 Worse
3 Don't Know

11. I am as happy as when I was younger.

1 Yes
2 No
3 Don't Know

12. How much do you feel lonely?

1 Very much
2 Not much
3 Don't Know

13. I see enough of my friends and relatives.

1 Yes
2 No
3 Don't Know

14. I sometimes feel that life isn't worth living.

1 Yes
2 No
3 Don't Know

15. Life is hard for me much of the time.

1 Yes
2 No
3 Don't Know

16. How satisfied are you with life today?

1 Satisfied
2 Not satisfied
3 Don't Know

17. I have a lot to be sad about.

1 Yes
2 No
3 Don't Know

PART V: PERCEIVED NEED FOR ADULT DAY PROGRAMS

The purpose of this next set of questions is to find out more about your needs.

1. What do you think life is like for people who live in a nursing home?

1 Very pleasant
2 Moderately pleasant
3 Both somewhat pleasant and unpleasant
4 Moderately unpleasant
5 Very unpleasant
6 Don't Know

2. Which of the following statements best describes how you would feel about the prospect of entering a nursing home ...

1 I would look forward to it
2 I would accept it because it would be easier for everyone all around
3 I would like to delay it as long as possible
4 I would never want to go
5 Don't Know

3. On average, how often do you leave your home?

1 Daily
2 At least 2 times per week
3 At least once a week
4 At least once every 2 weeks
5 Once a month or less
6 Don't Know

4. Have you ever heard of a program called an Adult Day Program?

1 Yes
2 No (IF NO GO TO Q.6)
3 Don't Know (GO TO Q.6)

5. IF YES, Have you ever gone to an Adult Day Program?

1 Yes, Please specify _____
2 No

6. Before we continue with more questions, I'd like to give you a brief description of what Adult Day Programs are all about. Adult Day Programs are a relatively new service for seniors who are not able to leave their homes very often because they have some kind of disability. An Adult Day Centre, therefore, is basically a safe place that you may go to for the day and participate in a wide variety of planned social and recreational activities. Other people at the centre would be similar to you in age and ability. Most of these centres are open twice a week or more, but it is up to you how often you attend. A hot meal is generally provided and some centres offer some health care services as well. One purpose of Adult Day Programs is to help seniors such as yourself who have disabilities to remain active and healthy members of the community. A second purpose is to give people who spend a lot of time caring for their elderly family member a day off.

7. From this description, what is your first impression of the idea of Adult Day Programs?

1 Excellent
2 Good
3 Fair
4 Poor
5 Don't Know

8. Is there anything that you like about the idea of Adult Day Programs?

1 Yes, Please specify _____
2 No
3 Don't Know

9. Is there anything that you dislike about the idea of Adult Day Programs?

1 Yes, Please specify _____
2 No
3 Don't Know

10. How strongly do you personally feel you need this program?

1 Very strongly
2 Fairly strongly
3 Not at all
4 Don't Know

11. How much do you believe that you would benefit from such a program?

1 Very much
2 Some
3 None
4 Don't Know

12. Now I am going to ask you if any of the following statements describes a need you currently have ...
PROBE AFTER EACH STATEMENT: Do you feel this need?

	Yes	No	DK
A I need to get out of the house more	1	2	3
B I need to meet new people			
C I need to give my caregiver a break			
D I need to do more leisure activities			
E I need some regular nursing care			
F I need to feel more useful/productive			

13. These needs have been placed on a set of cards. (SHOW RESPONDENT A CARD) Are you able to read this card? (IF NO, DO THE EXERCISE VERBALLY) Please put these cards in order, starting with the need you feel most strongly, and ending with the need you feel least strongly or not at all.

INTERVIEWER: RECORD LETTER ON CARD

1 _____ (most important)
2 _____
3 _____
4 _____
5 _____
6 _____ (least important)
7 couldn't rank

14. Using these same cards, I would like you to pick out which needs you think an Adult Day Program may help you to meet.

1 A
2 B
3 C
4 D
5 E
6 F
7 None
8 Don't Know

15. If you felt well enough and you were invited to attend an Adult Day Program next week to try it out, how strongly would you want to do so?

1 Very strongly
2 Fairly strongly
3 Not at all
4 Don't Know

16. What are the reasons you would not want to attend an Adult Day Program?

_____
_____
_____

PART VI: EXPECTATIONS OF ADULT DAY PROGRAMS

This section deals with what you would want in an Adult Day Program. When answering these questions, I would like you to think about what your needs are and what you enjoy doing.

1. Which of the following, to you, would be the ideal setting for your Adult Day Program?

1 In a nursing home
2 In a senior citizens' centre
3 In a school or community building
4 Other, Specify _____
5 Don't Know

2. How important is it to you that your Adult Day Program be close to your home (assuming transportation is available)?

1 Very important
2 Fairly important
3 Not at all important
4 Don't Know

3. Which of the following services would you want to receive at your Adult Day Program?

	Yes	No	DK
1 Hot lunch	1	2	3
2 Transportation to and from program			
3 Exercise group			
4 Arts and crafts groups			
5 Someone to dispense medication			
6 Rest period/place to rest			
7 Entertainment			
8 Opportunities to socialize with others			
9 Cards and games			
10 TV			
11 Volunteer opportunities			
12 Health education			
13 Individual counselling			
14 Bible study			
15 Personal care			
16 Trips to community events			
17 Health monitoring (b.p check, etc.)			
18 Bath			
19 Physiotherapy			
20 Others _____			
_____			
_____			

From this list (SHOW LARGE PRINT LIST OF SERVICES) rank order what you feel would be the 4 most important services.

1 _____
2 _____
3 _____
4 _____

PART VII: INTERVIEWER REMARKS*

Thank you very much for your participation in this study. If you are interested in the results that come out of this study or have any comments, here is a card with the name and number of the principal researcher.

INTERVIEWER COMPLETE THIS SECTION AS SOON AS POSSIBLE AFTER THE INTERVIEW.

1. Interview number: _____
2.. Interviewer's name: _____
3. Date of interview: _____
4. Length of interview: _____
5. Community: _____

6. Person interviewed:

1 Respondent alone
2 Respondent in the presence of another person
3 Respondent with some assistance of proxy
4 Respondent with much assistance of proxy

7. Respondent's attitude:

1 Friendly and cooperative
2 Suspicious or guarded on some questions
3 Suspicious or guarded in general
4 Undermined by proxy
5 Other, Specify _____

8. Respondent's state of mind:

1 Steady and strong in general
2 A bit weak or unsteady after some time in interview
3 Weak or unsteady in general
4 Undetermined (proxy involved)

9. Respondent's comprehension of questions:

   1 Satisfactory
   2 Fairly satisfactory
   3 Not satisfactory

10. Interview status:

   1 Complete
   2 Incomplete
   3 Refused
   4 Terminated

11. If the interview was terminated, state reason:

   _____

12. Other remarks:

   _____